

Tuberculosis and the Language of Culpability: 1870s to Present Day

Many people discriminate against tuberculosis patients out of a natural and universal fear that they themselves could be infected. However, these fears are often due to a pre-formulated prejudice based on instrumental and symbolic attitudes that have existed towards TB patients for centuries. Instrumental prejudice refers to the perceived material advantages and disadvantages that are caused by the existing relationship between the discriminator and the patient, and it often manifests as the perceived risk of infection. On the other hand, material prejudice refers to the potential gains and losses that an individual stands to suffer in the process of reaffirming the personal values that emanate from the interaction of the discriminator and the patient, especially when the discriminator fears being labeled poor or another stigmatized position just the same as the sufferer of TB¹. Inherently, discrimination and sustained stigma against TB patients often result from multiple sources, which are conjectured to translate into fear of infection or pollution, indifference, an association of the disease with abject poverty amongst other discrediting factors, which are known to contribute to the power differential often witnessed in the interaction between the affected and the uninfected. Naturally, there are several factors that contribute to the considerable ambivalence in the perceptions of both healthcare providers and family members as

¹ Bynum, H. (2012). *Spitting Blood: The History of Tuberculosis*. Oxford University Press.

they try to provide care for the ill while also consciously or unconsciously sustaining prejudices and discriminating activities against TB sufferers².

Most importantly, as the sustained prejudices against TB sufferers continue unabated, the afflicted have continually contended with the assigning of culpability for their affliction from the era before the tuberculosis bacillus was understood, in the nineteenth century, but which also pervades into the present day. Hence, historically individuals from lower social classes have been regarded as their own worst enemies based on their medical plight, the blame or which is projected onto them; thereby conveniently absolving from any blame those tasked with treatment responsibilities. More often, language used in reference to TB patients has been derogative and victimizing at best, with the medical community and existing support networks (such as sanitariums) adopting phrases to refer to the patients. Invariably, the language of choice sometimes appears accusatory with treatment support units, for the most part, universally calling patients some variation of “noncompliant chronic coughers who do not want to take their medicine or are in some way responsible for their own affliction in the first place”.

Unfortunately, medical professionals have therefore unwittingly contributed to the discrimination against TB patients based on name-calling and questionably ethical language lacking in empathy and condemning patients to either hide their symptoms, delay seeking therapy, or default from completing care due to the effect of the stigma imposed by the treatment support system and society at large to discriminate against and stigmatize TB patients. Consequently, the unfavorable coping mechanisms that evolved as a result of this iron dome of shame and condemnation often contribute significantly to sustained communal transmission and the subsequent emergence of TB strains resistant to antibiotic drugs. The primary purpose of this

² Ott, K. (1996). *Fevered lives: tuberculosis in American culture since 1870*. Harvard University Press.

paper is to seek and identify how the use of language projecting responsibility for TB infection on the sufferers has influenced treatment and management of the disease throughout modern history; specifically the period from 1870 to the present day³.

From the onset, this research will fundamentally aim to examine not just a single period when stigma-based on language use was extensive but also investigate the social phenomena associated with TB disease in different cultural settings. This paper will also attempt to take the current aggregate of literature regarding the treatment of TB patients through recent modern history and attempt to synthesize the existing material to consolidate a comprehensive, single and unique narrative that will highlight the salient matters often associated with language as a form of discrimination and stigmatization, that have been found to greatly influence health-seeking behavior, eventual prognosis and diagnosis of disease based on the progression and shifting linguistic trends of public perception, and the attitudes of medical professionals with regards to TB infection. Invariably, the current body of work will aim at synthesizing a cohesive linguistic history and demonstrate that several ideologies espoused by the language of culpability are indeed perpetrated by the healthcare support system of TB patients, including medical professionals and family members, who are critical to the point of establishing the social phenomenon of the language of culpability and guilt appropriating associated with tuberculosis infection in the late nineteenth, twentieth, and early twenty-first century..

According to Bynum (2012), the understanding society has attributed to the disease burden of TB has been problematic since the ancient world despite the fundamentally different understanding extant at the time relative to the modern comprehension of the disease⁴. The inherent difference in the modern understanding emanates from the transitions that societies have

³ Bynum, H. (2012). *Spitting Blood: The History of Tuberculosis*. Oxford University Press.

⁴ Bynum, H. (2012). *Spitting Blood: The History of Tuberculosis*. Oxford University Press.

undergone while also retaining their cultural perspective on the etiology, pathogenesis, treatment and management of TB. The diverse cultures in Asia, Europe, Africa and the Americas all have their unique way of identifying TB patients based on cultural belief systems, with some still entrenched in the traditional understanding that the occurrence of the disease was divinely inspired and treatable only through supplication to the gods, the result of poor moral character on the part of the inflicted, or due to some other perceived defect in the patient themselves beyond solely the infection. In ancient times, a TB sufferer was often thought to have angered the gods, and the disease was, therefore, a form of punishment from the deity due to human insolence, and a sufferer had to supplicate and pray to the gods for divine intervention⁵.

Beginning from the 5th Century BC, it was common to attach celestial explanations to the manifestation of TB symptoms, which would later change due to the advent of modernity characterized by evidence-based practice. In the ancient Hellenistic period, the temple cults were used purposely to facilitate healing of the afflicted, as they were believed to be under the spell of evil spirits. Essentially, at the same time, discrimination based on religious suspicions became widespread, with various groups of people promoting different postulations to justify why TB patients did not deserve to be kept close due to their “uncleanliness”. Hippocrates between 460-470 BC eventually introduced humor based medicine, which was primarily based on the theoretical notion of the configuration of bodily fluids and the dominant philosophy of matter. Hence, everything, including the human life was made up of four fundamental elements, which included fire, water, air and earth. If any of those aforementioned elements encountered a shift in

⁵ Tomes, N. (2002). Epidemic entertainments: Disease and popular culture in early-twentieth-century America. *American Literary History*, 14(4), 625-652.

normal functionality, there was a guaranteed equilibrium imbalance in the body functionality and TB patients were seen as bearing the consequences of their actions. Such conclusive thoughts on the plight of the afflicted continued unabated even into the modern times⁶.

During the 18th Century, there was no scientific word for TB but it became popularly known as “phthinein”, a condition that was associated with waning and physical erosion and was a medical terminology that implied atrophying, being consumed, declining from normal health, and even rotting in a literal sense. The normative application of this terminology to the public was labeling someone a “phthisic”. The concept of the slow body of consumption soon became the basis for disease references based on various names for those afflicted with the burden of the disorder⁷. It did not take long before it was commonly understood that it was apparent that every TB sufferer was undergoing internal decay of critical body organs. The term “melting away” not only became widespread among medical professionals but also found its roots in the public domain; thereby forming the fundamental basis upon which stereotyping associated with social class thrived. Musicians and poets would compose songs about someone dying from within while Aristophanes coined the term “consumptive” in his plays as an abusive term, while medically it was associated with a grievous consumption, which inexplicably took the soul away from the body⁸.

According to Ott (1996), the use of culpability language emanated from medical practice in the 1870s and 1880s, which was highly unregulated, and during which a consumptive patient

⁶ Bynum, H. (2012). *Spitting Blood: The History of Tuberculosis*. Oxford University Press.

⁷ Lawlor, C. (2006). *Consumption and Literature: The Making of the Romantic Disease*.

⁸ Bynum, H. (2012). *Spitting Blood: The History of Tuberculosis*. Oxford University Press.

could consult anybody within the medical field⁹. For instance, a person could consult a homoeopath, allopath, and osteopath, amongst other practitioners who had ventured into obscure medical practices. The medical anarchy that existed during the 1880s made tuberculosis a speculative disease that was attached to several notions, hence the resulting ostracization extant even in the language of use when referring to the comorbidities associated with tuberculosis. Soon, diagnostic procedures, which were less informed with scientific evidence, formed the basis of stereotyping that largely depended on the patient's temperament during the presentation of the disease¹⁰. The stereotyping therefore influenced even how patients would be treated by the society around them, based on the perceived temperament of the patients. In the past as in modern times, the role of the physicians in influencing public perception, and the language of culpability they largely cultivated was significant in informing the attitudes of common people about the disease. Terms such as “wasting”, “fever”, and even “lung lesions” epitomized by incessant coughing helped to inform public opinion especially given the reports that depicted TB as a dangerous and highly contagious disease. Stereotyping soon targeted the afflicted's racial origins, with African-Americans being touted as the most high-risk population associated with factors such as poor hygiene, poverty, and weak immune system.

Ott (1996) in his book “Fevered Lives” postulated that TB immunity and prevalence patterns often mirrored different ethnic communities' escalating racial fears and prejudices¹¹. For instance, the Boston Commission to Investigate the Sanitary Condition of the City promoted

⁹ Ott, K. (1996). *Fevered lives: tuberculosis in American culture since 1870*. Harvard University Press.

¹⁰ Lerner, B. H. (1997). From careless consumptives to recalcitrant patients: the historical construction of noncompliance. *Social Science & Medicine*, 45(9), 1423-1431.

¹¹ Ott, K. (1996). *Fevered lives: tuberculosis in American culture since 1870*. Harvard University Press.

profiling of innocent citizens. The Irish were described as highly susceptible to all groups of TB and were therefore considered a high-risk population alongside African Americans. In its postulations, the commission made claims that TB was essentially caused by “constitution” and that all the individuals believed to be highly susceptible either inherited the disease or acquired it solely on the basis of their nationality and the “constitution” associated with it, in what we might today call a Social Darwinian sense. Other communities were made to believe the notion that they were peculiarly immune to the disease and that no amount of exposure would cause them to acquire TB as a result of their superior constitution. Similarly, anti-Semitic views such as the belief that Jews were comparatively exempt from diseases such as consumption and scrofula were propagated and used to motivate anti-Jewish sentiment within European communities¹². Alternatively, the concerns of racially inherited predispositions intensified the language of culpability and prejudices especially against the immigrants that were commonly traveling across Europe and into the United States. For example, people from Southern China who had gone to the West Coast of the United States were either accused of bringing unwanted disease with them or being high-risk emigrants due to the poverty that was associated with China at the beginning of the 19th Century. Somewhat paradoxically, especially compared to European sentiment, European Jews in the Northeast United States were also accused of being carriers of TB and propagating it in cities like New York City¹³.

The projection of responsibility for the onset of TB among its sufferers invariably aligned the societies in question with the prevailing social injustices foisted upon TB sufferers, and

¹² Lawlor, C. (2006). *Consumption and Literature: The Making of the Romantic Disease*. Springer.

¹³ Ott, K. (1996). *Fevered lives: tuberculosis in American culture since 1870*. Harvard University Press.

consequently made healthy people distance themselves from individuals believed to be not just responsible, but culpable, for its spread. TB, which has affected the poor and other minority groups since its discovery, with the wealthy often spared the suffering of TB patients, has been a discriminatory disease by its very nature, promoting the socialization of these views among the population. Though one might imagine that there is an active conspiracy of sorts within the medical community against the tuberculosis-stricken, the truth is that the existing societal beliefs endemic to the late nineteenth century served to often shift blame for the existence of the TB disease and its outbreaks whenever they occur onto those who are its primary victims¹⁴. The blame game has also evolved with even medical practitioners, who are expected to act and behave differently, taking a central position in fueling unwarranted prejudice against their patients. The lack of empathy from the available treatment support systems is, therefore, the reason why patients found it difficult to cope with their treatment options, as they find it hard to accommodate the abusive and judgmental nature of some often used medical terminologies. The term “constitution” which has been used continually to refer to the indigents alludes to the poor and other races as socially insignificant and disease prone therefore shifting the blame of the broader societal disease burden and treatment from the responsible social and institutional structures to the sufferers themselves. For instance, the continued cross-reference of African Americans as weaklings of the inferior constitution that makes them disproportionately susceptible to contracting TB only manages to reinforce the inherent racism in the context of the period it was widely popular during, namely the 19th century¹⁵.

¹⁴ Bynum, H. (2012). *Spitting Blood: The History of Tuberculosis*. Oxford University Press.

¹⁵ Tomes, N. (2002). Epidemic entertainments: Disease and popular culture in early-twentieth-century America. *American Literary History*, 14(4), 625-652.

Allocation of blame or culpability to the stricken communities serves agenda of the medical establishment to distance itself from accusations that they could have faced in their repeated failures at containing an outbreak, especially among the vulnerable communities. Culpability language has also progressed following the controversial usage of some words that appear cogent to the medical profession but ethically wrong to the patients who attempted to highlight their offensive nature throughout the time of the affliction. Therefore, it is prudent to consider that there have been efforts made by the healthcare policy in order to be more sensitive and neutral when discharging their diagnostic and treatment obligations as healthcare professionals. Unfortunately, the derogative, judgmental, and sometimes criminalizing terms such as "TB suspect" used to refer to tuberculosis patients have pervaded well into the modern day.

While expounding on the concept of the "constitution", it is imperative to realize that it is a phenomenon that was considered a legitimate indicator of the risk of developing TB for the entirety of the nineteenth century and the first two decades of the twentieth. In the years preceding Koch's discoveries and subsequent publications on the nature of the tubercle bacillus, the concept of "constitution" was reserved for those who were believed to be carriers of the disease and therefore infectious to the rest of the population. The term would then be used to refer to the destitute and ethnically marginalized members of the society afflicted with TB, especially the racial minorities. Most significantly, anyone referred to as "possessing a weak constitution" or befitting a similar title during the 1880s was treated in many ways as a social pariah, and it was often not socially acceptable for them to mingle with the general population, lest they be called names and even further victimized for having the disease. The Western societies of the world in which this was most eminent, specifically the US, were therefore

socialized to treat TB sufferers with suspicion due to their perceived inferiority. Medically, the term “constitution” resulted in the foregone conclusion that all TB patients were, in fact, responsible for their fate, attributable to their weak characters. All assorted terminologies that were consequently used to describe the TB patients emanated from the understanding that it was justifiable to do that despite its abject accusation of the infected being vulnerable to infection partly due to their individual attributes.

In the final decades of the 19th Century, the culpability language progressed a few notches further and pervaded the following years throughout the 20th century. The new era of modernity replaced “constitution” with the attribution of accountability to the sufferer of TB infection due to the broader “persona” of the individual afflicted, leading to the “consumptive persona” phenomenon¹⁶. The new terminology was associated with people focusing on the outward image of the sufferer as belonging to the individuals who were most affected by consumption. The preoccupation of consumption with the lower class created an ironical indifference epitomized by the upper echelons of society glorifying the associated symptoms of the disease if one of their own was dying of the disease, but simultaneously treating the lower class victims of the same disease as essentially rotting carcasses, responsible for their own infection. In fact, the elite in the US romanticized every element of TB ailment, with the paleness of the skin associated with the latter stages of the disease and physical attributes of wasting away viewed as part of an artistic endeavor or as possessing some sort of essential aesthetic quality. In

¹⁶ Lerner, B. H. (1997). From careless consumptives to recalcitrant patients: the historical construction of noncompliance. *Social Science & Medicine*, 45(9), 1423-1431.

stark contrast, much negativity was often associated with those who were considered poor and suffering from TB. Other negative comments that were repeatedly used against these unfortunate patients included words such as unclean, contaminated, filthy, “rotting pieces of flesh” and “disease prone weaklings”¹⁷.

One critical aspect of the consumptive persona was the premeditated social stigmatization targeting specific groups that had been affected with TB and reflecting their lives as impure, hence their susceptibility to the afflictions that riddled their bodies; thus rendering them the perceived “persona non-grata” of the society. Throughout the 19th Century, from the perspective of much of society all the TB patients that had manifested symptoms were morally impure and had no basis to exist due to their moral inferiority as illustrated by the fact that they were plagued with consumption and other antecedents that the upper class felt they were immune to and therefore could not suffer from. The middle class also managed to absolve the medical community from their inability to cure TB and contain outbreaks within the population through the shifting of blame from inadequate public health policy, and poor medical professionals, to the moral inferiority of the sufferers¹⁸. Around the late 1880s, Koch’s germ theory had become popular among the medical community and the public. Koch’s theory espoused the need for commiseration on the devastating nature of the tuberculosis a dismissed the empirically unsupportable “constitution” phenomenon.

¹⁷ Lawlor, C. (2006). *Consumption and Literature: The Making of the Romantic Disease*.

Springer.

¹⁸ Lawlor, C. (2006). *Consumption and Literature: The Making of the Romantic Disease*.

Springer.

According to Lerner (1997), Koch took a more theoretical and practical approach to demystify the long-held beliefs that people had associated with TB¹⁹. The constitution theory was, however, debunked based on what Koch would later explain in his postulations concerning TB was in fact to be blamed on a host of predisposing factors, but primarily on the bacteria, then called the tubercle bacillus, which was responsible for the numerous infections witnessed in the 19th Century and the disease as a whole. Since bacterial infection could not be blamed entirely on an individual, it became evident that there were some other perpetuating factors that made consumption possible based on individual qualities, such as hygiene²⁰. The beginning of 20th century was soon marked by greater cognizance of the disease's progression and treatment opportunities that could contain the disease. The discriminatory nature of the term "consumption" also reduced significantly as people learnt about TB and became more aware of it and its causes²¹. Invariably, the discriminating nature of the disease became milder and transitioned from a near complete blame of the disease on a group's personal attributes and

¹⁹ Lerner, B. H. (1997). From careless consumptives to recalcitrant patients: the historical construction of noncompliance. *Social Science & Medicine*, 45(9), 1423-1431.

²⁰ Lawlor, C. (2006). *Consumption and Literature: The Making of the Romantic Disease*. Springer.

²¹ Zachariah, R., Harries, A. D., Srinath, S., Ram, S., Viney, K., Singogo, E., ... & Sharath, B. N.(2012). Language in tuberculosis services: can we change to patient-centered terminology and stop the paradigm of blaming the patients?[Perspectives]. *The International Journal of Tuberculosis and Lung Disease*, 16(6), 714-717.

susceptibility to the oblique blame of TB on behavioral tendencies, another characteristic often associated with the consumptive behavior.

In recent years, the direct blame of TB on the patient has not abated but has progressed along a “euphemism treadmill”, simply replacing offensive terms with softer, gentler words meant to mean the same thing. Currently, the medical community has been at the center of the modern controversy on the language of stigmatization of the TB patients especially with regards to the impression created among the general public that TB patients are inherently troublesome and often not ready to cooperate during treatment. The most recent terminology often used by the medical community to initiate a vicious cycle of blame is the use of the word “non-compliance”, which is often applied to TB patients in reference to their stubborn nature in refusing to complete treatment.

The term “non-compliance” emerged during the era of medical innovation in the 1940s, 1947 in this case to be specific, during which streptomycin was discovered as the first antibiotic that was appropriate for the treatment of tuberculosis. The term “non-compliance” also alludes to the fact that a patient’s treatment outcomes are solely based on their cooperation and primarily upon them, since they are the ones in need of curing. Invariably, the term refers to a patient who for whatever reason is perceived as making little or no efforts to get well by either not taking drugs as prescribed or not following instructions as provided by their physicians²². Arguably, the term “noncompliance” has been regarded as demanding and incriminatory in the sense that it is

²² Fried, C. (2016). *Medical Experimentation: Personal Integrity and Social Policy: New Edition*. Oxford University Press.

geared towards evoking guilt and driving patients towards “taking responsibility for one's own disease burden”.

In recent years, the application of "noncompliance" has been used to ostensibly refer to a particular distinction that makes TB patients more conspicuous to the medical community than sufferers of other infections. As a consequence of this particular distinction made by the medical community, patients have become the targets of unsavory remarks based on their socioeconomic backgrounds, and many would argue that they are also racially profiled. During racial profiling, most propagators of stigma use racial undertones to project accountability onto the patient. One thing that has often remained a part of the disease history among discriminators is a failure to understand that their discrimination and derogatory remarks essentially emanate from historical discrimination and injustices that influenced the current TB trends, such as the historical discrimination that has made poverty, a major risk factor for TB, much more prevalent among the African American community. Therefore, noncompliance cannot be blamed entirely on the TB patients, since there are many underlying factors that contribute to the disease.

Noncompliance has often been associated with African Americans, Hispanics and other minority groups due to their poor social and economic grounds and as highly vulnerable populations.

Correspondingly, given the discrimination in language use, the medical community has continually failed to limit the damage caused by their language of culpability, yet the current vulnerable groups have lived with their problems for centuries without any kind of restitution²³.

For instance, many marginalized groups in the US lack access to quality and affordable healthcare compared to their wealthier counterparts. Medical coverage in the US remains a challenge to minority groups, hence an increasing vulnerability towards diseases such as TB, as

²³ Ott, K. (1996). *Fevered lives: tuberculosis in American culture since 1870*. Harvard University Press.

well as poorer prognoses for those already infected with tuberculosis. Due to their poverty, poor housing, and hygiene challenges many of these vulnerable groups are similarly condemned to contracting other communicable and non-communicable diseases whose mortality rates have also skyrocketed²⁴. Conversely, the same groups that have been termed repeatedly by the medical field as noncompliant and reckless have existed within the sort of historical legacy that has bred mistrust towards physicians by patients belonging to these marginalized groups; ultimately resulting in higher rates of medical noncompliance in relation to treatment and treatment outcomes. The disparity in care provision, therefore, has continued to victimize the vulnerable groups, and mistreat them if no appropriate action is taken to understand the consequences of discrimination towards TB patients regarding health-seeking behavior and treatment outcomes. The most recent language preferred to index clients contributes to the existing social view of culpability given its reliance on the notion that chronic TB infection happens only to patients who do not comply with treatment, when such an opportunity is presented to them.

The dawn of modernity greatly enhanced scientific and technological innovations that made the diagnosis and treatment of TB more efficient. Understandably, the medical field has consequently become the center of controversy for promoting presumptive ideologies that inadvertently fueled prejudices. In the most era, namely the past three decades, it has been common to hear terms such as “defaulter”, “suspect”, “control” and “contagious” in the language of tuberculosis treatment, which are in fact progressions of the same discriminatory and bigoted ideologies of the 1880s to 1950s, which have been going on for decades and continue to be used

²⁴ Tomes, N. (2002). Epidemic entertainments: Disease and popular culture in early-twentieth-century America. *American Literary History*, 14(4), 625-652.

globally in line with international guidelines and health policies, despite their rather transparent status as simply the “next step” on the euphemism treadmill of the language of patient culpability. Viewed from a patient’s perspective, controversies have always rocked the medical community regarding the usage of such terms, which appear discriminatory, derogative and inhumane, as well as lacking empathy when used often to refer to patients. Patients have specifically blamed the use of such language as the reasons they defaulted on their TB treatment, since they felt targeted by the healthcare providers, who appeared to be ridiculing their unfortunate state of wellbeing. The use of culpability language has therefore been unyielding and continually present well into the twenty-first century. In extreme instances, it has been viewed as highly judgmental. In fact, many doctors writing on the topic have suggested that this language only serves to “criminalize a disease” patients obviously did not wish to acquire in the first place. The use of terms meant to project blame onto patients for their health problems also translates socially into forcing patients to take the blame for diseases they did not wish upon themselves²⁵.

Often used in a clinical setting, the term “defaulter” refers to an ill person who advertently or inadvertently fails to fulfill the obligations or duty they are expected to fill with regards to their treatment. The term has gained prominence especially among TB patients seeking treatment for their disease, and it is popularly used within healthcare institutions the care providers in an official capacity, demonstrating that the issues associated with the language of culpability are institutional rather than purely individual. Predictably, the term “defaulter” is used categorically within the context of TB mostly to unnecessarily and unfairly place all the blame for the

²⁵ Fried, C. (2016). *Medical Experimentation: Personal Integrity and Social Policy: New Edition*. Oxford University Press.

impartial and normatively immaterial infection on the TB patient. A “defaulter” is, therefore, a TB patient, male or female, who has been documented as being sputum smear positive for all the acid-fast bacilli tests according to the lab results, but who does not appear in the designated TB registry and have therefore not been initiated into the treatment. In essence, a defaulter based on the first definition implies that such a patient has been to a TB clinic and diagnosed with the disease, but that they are not registered for the initiation of treatment. Despite the well documented causal factors responsible for defaulting among TB patients, it is critical to realize that the first time a TB patient defaults, there is almost a 100% chance that the health care services being offered by the healthcare institution are of poor quality and therefore do not effectively support the initiation of treatment²⁶.

Inherently poor quality services at the healthcare facilities frequented by modern tuberculosis sufferers, such as free clinics, and other medical institutions aimed at providing care for the impoverished, are characterized by a lack of drug commodities, which are often out of stock or the result of medical errors committed by healthcare workers themselves. Most importantly, it becomes a serious breach of professionalism when healthcare institutions fail the patient by not doing the needed diagnostic paperwork and registration for treatment based on stringent standard operating procedures, rather than the subjective and lower quality care often conferred onto TB patients due to endemic prejudices in the medical community. In most

²⁶ Zachariah, R., Harries, A. D., Srinath, S., Ram, S., Viney, K., Singogo, E., ... & Sharath, B.

N.(2012). Language in tuberculosis services: can we change to patient-centered terminology and stop the paradigm of blaming the patients?[Perspectives]. *The International Journal of Tuberculosis and Lung Disease*, 16(6), 714-717.

instances, the healthcare institutions fail in their obligation to the patient; thereby using it as a fundamental basis from which to shift blame and place it on the patients by wrongly labelling them as “initial defaulters”. Moreover, most national TB programs fail to include “initial defaulters” when making reports and reporting on national TB outcomes. The reason why non-reporting and the documentation of TB outcomes have a severe impact on TB patients is that underreporting adversely influences the desired outcomes for cure and treatment of TB related indicators, which are inevitably reported as declining medical and public health publications.

The second meaning of a “defaulter” refers to the treatment of a defaulter who has been initiated into a TB treatment program but fails to complete it on a designated basis or interrupts the course within the first two months of treatment or more. Failure to complete treatment even if the patient has been started on anti-TB drugs emanates from several shortcomings that are inherent to every healthcare system. Such problems are deterrents to effective completion of TB treatment, and the patients usually have no control over them²⁷. The perceived and actual shortcomings entail staff attitude, quality of service provision, cultural obstacles, social stigmatization and financial setbacks. In some instance, failure to complete the recommended treatment regimen could be based solely on the lack of a regular drug supply to the TB patients who are already on treatment and the absence of government or organizational incentives in terms of subsidies to reduce costs associated with the purchase of various TB antibiotics. This forces low income patients to pay, and in most instances abscond treatment due to poverty.

²⁷ Tomes, N. (2002). Epidemic entertainments: Disease and popular culture in early-twentieth-century America. *American Literary History*, 14(4), 625-652.

Accessibility to quality healthcare services has also been critical in determining outcomes as to a TB patient's completion of treatment successfully without defaulting and including ambulatory services and the patient's perceived proximity to the point of care. Other auxiliary factors that prevent completion of treatment include long waiting hours, lack of patient education and the inexistence of alternative forms of treatment for severely ill facility based patients²⁸. The mentioned challenges that prevent TB patients from completing treatment act as clear indicators as to the lack of a strong and effective patient-centered approach towards the management of tuberculosis at the facility level and are probably the reasons for most incomplete treatment rates. It is therefore imperative to realize that without strong healthcare and referral systems the patient outcomes and measurable TB indicators will continue descending along a downward trend unless healthcare systems take a different and affirmative action and do not address the issues affecting clients who come to seek awareness and elucidation concerning their disease. Patient education is also critical towards understanding tuberculosis as a disease and how it can be managed effectively at a personal level while also reducing the probability of reinfection.

The stigmatization and criminalization of TB has often thrived on the paternalistic approach taken by public health officials in the decision-making processes on behalf of TB patients and the community at large. The moment these patients are empowered to become independent and autonomous in their quest for health and disease-free lives, TB indicators will

²⁸ Zachariah, R., Harries, A. D., Srinath, S., Ram, S., Viney, K., Singogo, E., ... & Sharath, B.

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improve and the persistent use of demeaning language within the healthcare industry will invariably decrease. Awareness, therefore, is not only a prerogative of the healthcare complex but also with regards to their TB patients, who are in most instances battling other serious healthcare conditions. In the modern world, it is still hard to believe that numerous TB strategies have often backfired since their primary focus has been centered on the service provider as the supreme authority. The need for a patient-centered approach in addressing the language of culpability surrounding the treatment of tuberculosis will go a long way in ensuring that patients who have been registered for treatment and have subsequently started the therapy will eventually complete their treatment without any hitches since care will be based on respect and dignity towards the sufferer as opposed to the appropriation of blame onto patients during treatment and management.

The third attribute focusing on the term “defaulter” defines the patient as someone who had initially started TB treatment and has subsequently interrupted therapy on the anti-TB drugs for a period of two months or more before returning back to care for treatment²⁹. The postulations already highlighted herein and the implications of the language used within the clinical setup remain valid for the group of patients falling into this category. From the foregoing discussions, it is prudent to propose that terminologies that have been criminalizing TB patients and making completion of treatment quite difficult to achieve ought to be replaced by positive and more

²⁹ Zachariah, R., Harries, A. D., Srinath, S., Ram, S., Viney, K., Singogo, E., ... & Sharath, B.

N.(2012). Language in tuberculosis services: can we change to patient-centered terminology and stop the paradigm of blaming the patients?[Perspectives]. *The International Journal of Tuberculosis and Lung Disease*, 16(6), 714-717.

dignified terms such as “lost to follow up” for a defaulter. The term “lost to follow up” is not judgmental but is used only to describe the outcome of treatment thereby highlighting the responsibilities of the service providers and the medical community at large to maintain an enabling patient-focused environment where patients are less likely to be lost to follow up³⁰. Further suggestions can be made with respect to the point that the terms, which had been used but not appropriated within the clinical setup be replaced with others such as “pre-treatment loss to follow up” for patients who have not started treatment and are not registered, “loss to follow up” for patients who have started therapy but have dropped out of the treatment program, and “return to care” for patients who had started therapy but stopped the treatment regimen due to the underlying factors already highlighted herein.

Another terminology that has consistently been used to vilify TB patients and make them appear as criminals and deviants throughout recent history is "TB Suspect". This is an adjective and noun with several meanings and usages depending on the context of its application. The impression created by the term often elicits mixed reactions when used in TB healthcare service language. It defines a TB patient who is already presenting symptoms of illness suggestive of tuberculosis and has been used by the medical community for decades. The term is subjective and underlines a finality of judgment emanating from suspicions of the disease in a potential patient. By presenting the symptoms for TB, the patients are condemned to a guilty conscience of a crime or offence exhibited by their condition. Though several reforms have been instituted to designate universal health care terminologies, as used in a clinical context, some conditions

³⁰ Fried, C. (2016). *Medical Experimentation: Personal Integrity and Social Policy: New Edition*. Oxford University Press.

are never mentioned with the tag “suspect” attached to them. It is extraordinarily uncommon to hear of “HIV suspects”, “Cancer suspects”, or “Syphilis suspects” among a host of other related conditions. The reason for this is that the consequences that an institution can suffer in terms of litigation by disregarding patient confidentiality and privacy to medical records. The bias, therefore, seems to be engraved upon TB as a disease, which was for a long time equated with conditions such as leprosy, possessing huge stigmas and resulting en masse social ostracization of sufferers. The continued use of the term “TB suspect” has only added more stigmatization and criminalization of the disease sufferers who are vulnerable and exposed to several medical conditions associated with TB. Moreover, the term “TB suspect” has often been used in reference to patients who have been found to be resistant to drugs and who are prone to the recurrence of the same condition even if they complete a treatment regimen as prescribed by a practicing physician³¹. It is therefore proposed that to fight sustained stigmatization based on the use of the language of culpability, national and global ministries of health should implement health care policies that will redefine terms of references (ToF) used within the medical community. The term “TB suspect” can be replaced by a more neutral and nonjudgmental term in the form of “a patient with possible TB” or “presumptive TB” or “a person to be evaluated for TB”, which while more verbose, divorce themselves from the ugly history of socio-linguistic discrimination against tuberculosis patients.

³¹ Zachariah, R., Harries, A. D., Srinath, S., Ram, S., Viney, K., Singogo, E., ... & Sharath, B. N.(2012). Language in tuberculosis services: can we change to patient-centered terminology and stop the paradigm of blaming the patients?[Perspectives]. *The International Journal of Tuberculosis and Lung Disease*, 16(6), 714-717.

Most governments and non-governmental agencies have repeatedly promoted, or ignored, discrimination against people suffering from TB, arguably in a state of unawareness with regards to the pitfalls of their activities, even if these organizations ultimately aim to eradicate the disease's incidence and prevalence among the populations. It is often common to hear of several TB programs having the term "control" in their manifestos. The term "control" defines the mission and vision of these entities. In the context of TB prevalence, "control" refers to the need to principally limit, maintain or influence using authority to shift and modify behavior³². Hence, the notion of control sets a dangerous precedent in its usage and application as it supposes to potentially place power in the hands of historically discriminatory healthcare providers; thus making them experts and the driving force behind solving existing health care problems. The notion of control as an overarching and commanding authority can lead healthcare providers and decision-makers to overlook and neglect the community and related patient resources. Continued use of the term "control" alludes to a very toxic situation needing mitigation, which correspondingly places TB patients in a difficult position, as the community support base does not necessarily view it from the disease perspective but from the patient's point of view. It also alludes to the fact that since TB is highly infectious, those that are found to be manifesting its symptoms need to be somehow "controlled" or even "quarantined" to contain the spread of the disease. However, when physical control is applied by the program implementers, they often end

³² Zachariah, R., Harries, A. D., Srinath, S., Ram, S., Viney, K., Singogo, E., ... & Sharath, B.

N.(2012). Language in tuberculosis services: can we change to patient-centered terminology and stop the paradigm of blaming the patients?[Perspectives]. *The International Journal of Tuberculosis and Lung Disease*, 16(6), 714-717.

up arguably infringing on the rights of the patient with regards to personal autonomy, movement and association with the rest of the population. Furthermore, when the term “control” is used to refer to TB programs, the affected community and even the patients can interpret it as something being conducted on the patient and respond negatively, hence the resulting justification for coercive actions aimed at influencing patient behavior³³.

The term “control” is often used within the medical field for national TB control programs and could be fundamentally linked to the history of the management of the disease, which has often taken an institutionalized approach as opposed to a patient-focused approach. Though one could easily argue that the use of the term “control” has been implemented repeatedly to achieve considerable epidemic control, the perspective of disease control in and of itself should come from an understanding that prevention and treatment are the services offered by TB programs, built upon an aspirational model that seeks to avoid the derogatory and stigmatizing pitfalls of past attempts. It is therefore imperative for modern national tuberculosis treatment programs to adopt more neutral and accommodative terminologies such as “prevention and treatment” instead of “control” in describing their program based activities. The national programs could also add the term “care” as it highlights the notion of a patient-centered approach to the management of TB³⁴.

³³ Fried, C. (2016). *Medical Experimentation: Personal Integrity and Social Policy: New Edition*. Oxford University Press.

³⁴ Zachariah, R., Harries, A. D., Srinath, S., Ram, S., Viney, K., Singogo, E., ... & Sharath, B. N. (2012). Language in tuberculosis services: can we change to patient-centered

The terminologies highlighted, both from the community perspective, to the medical field show an existing trend of sustained stigmatization and discrimination against TB patients and social vernacular and medical terminology primarily projecting culpability for the illness onto the patient, treating them as if they are solely responsible for their conditions, and no professional or institutional barriers existed. It is therefore prudent to take appropriate measures to address the inherent and systemic abuse suffered historically by TB patients. The prerogative of the medical field is therefore aimed at adopting a more patient-centered approach in the treatment and management of TB patients. When the language of culpability is avoided, TB patients will experience an improved quality of care, which correspondingly translates into an enhanced healthcare outcome and a higher quality of life. A policy of dignified and humane treatment of TB patients is, therefore, an obligation of the local community and the medical community as well in eliminating societal and intuitional stigmas, which have often thrived on their usage of overtly bigoted terms of references. The progression towards dignified language usage in describing situations in which a patient is viewed to be responsible for their own struggles with TB in some way is reflective of the general trend towards understanding and improvement in patient care within those communities most affected in recent years; suggesting an upward trend in the quality of care offered to this historically beleaguered group.

terminology and stop the paradigm of blaming the patients?[Perspectives]. *The International Journal of Tuberculosis and Lung Disease*, 16(6), 714-717.

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